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ABSTRACT

This paper describes an exhibit, "Layered Worlds: The Look of Alzheimer's," which uses photography as the medium to interpret Alzheimer's disease visually. The goal was not to photograph the victims of the disease, but to interpret the experience of Alzheimer's for the patient, family members, and caregivers. The metaphor of layers was used to convey the experience of a world of time--of layers of past, present, and future, out of touch with one another, and whose sequence is out of kilter. Images with shallow depth of field expressed the world of both patient and caregiver, a world where a momentary glimpse of recognition is surrounded by fogginess and the blur of forgetting. Carousel images conveyed the confusion as well as the dignity of the patient. Images reflected in windows were used to show the experience of family members who move in and out of varied worlds, the day-to-day world with its cares and responsibilities and that of the patient, a world of its own. A series of "cranberry" photographs, with rich colors and sharp images, spoke of a life to be affirmed. The work of other artists who have interpreted this disease are mentioned as well. (DGM)

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Layered Worlds: A Metaphor of Time, Visualizing the Experience of Alzheimer's

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Ann M. Grady

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Time out of sequence. . .The past overtakes the present. . .The pace picks up. . . The present becomes a blur.

Alzheimer's, a disease which alters judgment, memory, and understanding, interrupts our human experience of time. As a daughter whose mother lived with Alzheimer's disease for 10 years, I recently chose to use photography as the medium to interpret Alzheimer's visually. Photography, the guardian of our memories, entrusted with our past and present, bequeathed with memories for future generations was a medium suited for interpreting that disease which sharply disturbs those memories, those hopes for the future.

A LAYERED WORLD
that holds richness
and threat alike
in its grasp -
that is the experience
of this exhibit.
That is the experience of
Alzheimer patient
and caregiver alike.
These images invite you
to enter that world.

In this article I will verbalize, as much as possible, my work of visual interpretation that culminated in an exhibit, *Layered Worlds: The Look of Alzheimer's* which was presented in the Carney Gallery, Fine Arts Center, at Regis College, Weston, MA, March 14 - May 23, 1994.[1] I will conclude with mention of works of other artists who have been involved in a similar endeavor – both visual and verbal.

Photography Guardian of Memory?

The camera turned to capture faces of Alzheimer's was not my choice. The look of Alzheimer's on the face of the victim of the disease spoke too strongly of what had been lost. That I did not want to photograph. To photograph that look of Alzheimer's seemed to reinflict the pain of the disease once again.

There was another look of

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Alzheimer's that I set to interpreting. I looked to interpret the experience of Alzheimer's disease for patient, for family members, for caregivers. What does the experience look like? What is the experience of Alzheimer's and how can that be visualized?

A Disrupted World of Time

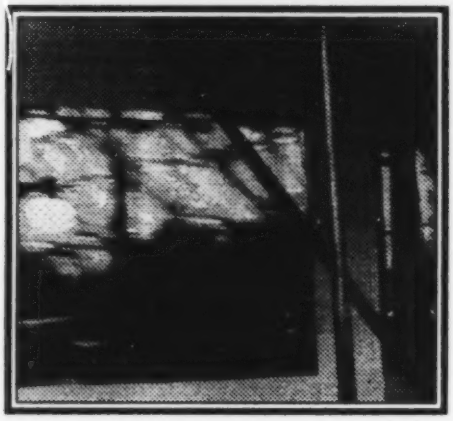
As one who is at home in the world of metaphor, I sought an image that could convey the experience of a world of time, a world of layers of past, present and future, layers that are at times out of touch with each other, layers whose sequence is often out of kilter.

The camera proved to be a very apt medium for my message. The world of nature, of windows and carousels seen through the lens of the camera became transformed. I was able to utilize the capabilities of the technology as a means to explore and express the Alzheimer experience. Shallow depth of field, the blur of motion, the shadows and textures created by back lighting, worlds reflected in windows, moments frozen in time - these were the tools which allowed me to explore the world of Alzheimer's. Once I had set myself the task of utilizing the metaphor of a layered world, I was able to explore some of the varied manifestations of the disease as well as the many moments in the lives of patients and caregivers where the experience of time is integral.

Worlds In and Out of Focus

Images with shallow depth of field conveyed the world of both patient and caregiver, a world where a momentary glimpse of recognition is surrounded by the fogginess, the blur of forgetting. The lack of recognition by the Alzheimer patient who cannot make the connections is mimicked in the experience of family and caregiver who now only catch momentary glimpses of the person they know and love. The one moment of recognition when the patient knows who you are epitomizes the layers of time that are constantly moving in and out of focus. That moment of recognition will later be followed by blur, a world in which things and people are no longer clear.

Some images in the exhibit convey the blur of motion, a blur experienced during the progression of the disease when the pace of life picks up. Caregiver and patient alike feel as if they



are propelled headlong into an uncertain future. The blur of images taken from the moving carousel proved to be rich images to convey the confusion as well as the dignity of the person trying to survive. The head of the horse on the carousel seems to move courageously into the world, which has now become a blur.

Time's Sequence Gone Wrong

The disease often and abruptly moves people back to another time, another place. At other moments patient and caregiver alike are propelled into a world where the normal pace of time is speeded up. Past, future, present seem to be moving in the wrong direction. It is hard to tell if one is moving from today to tomorrow or to yesterday. The carousel horses that appear to be moving in all directions at the same time epitomize for me this experience of Alzheimer's.

Into Another Time, Another Place

Images reflected in windows were interesting images. Such beauty – but also a world in which one is not certain where one layer of reality begins and another leaves off. For me the images in the window expressed the experience of family members, always moving in and out of varied worlds – the day to day world with its cares and responsibilities and the world of the patient, which at some moments during the disease, manifests a beauty, a world of its own. The world of the patient does not share the same rules as the world of daily life. However, it has to be accepted as the world of the patient – no matter how ephemeral it might seem to another onlooker.

An Affirmation of Time

As difficult as the disease is for all touched by it, it is also important to notice the moments of respite, moments when for however brief a space, time seemed to settle back into its normal sequence. The cranberry series with its sharp images and rich colors spoke

clearly of a life to be affirmed. People and events were able to be recognized for what they had been. Glimpses of the life that had been were able to emerge.

Works of Other Artists

Other artists – both visual and verbal – have also worked at interpreting the experience of this disease. Elie Wiesel, in his novel *The Forgotten* uses images of sieves, of autumn leaves to convey the experience of a mind that is losing its former abilities.[2] Annie Ernaux, in her work, *A Woman's Story*, recounts incident after incident from the life of her mother that epitomize what is lost.[3] These incidents give flesh to the experiences behind the metaphors in my exhibit.

Even in the work of a photographer, Nicholas deCandia, who chose to photograph a woman who was experiencing Alzheimer's, we see him reaching for words and images that embrace the experience of the disease. In his large collage, **fragmentation** is the predominant image, trying to mirror back some of the experience for patient and caregivers alike.[4]

Printmaker, Eleanor Rubin, together with her sisters, Joanne Leonard and Barbara Handelman, presented visual and verbal interpretations while they were in the midst of living through their mother's experience of Alzheimer's.[5] The comments of their mother's physician embody the layered world that is Alzheimer's when he said, "Listening to your mother is like coming across cathedrals still standing in a bombed-out city."[6]

A World of Great Achievement as well as Devastation

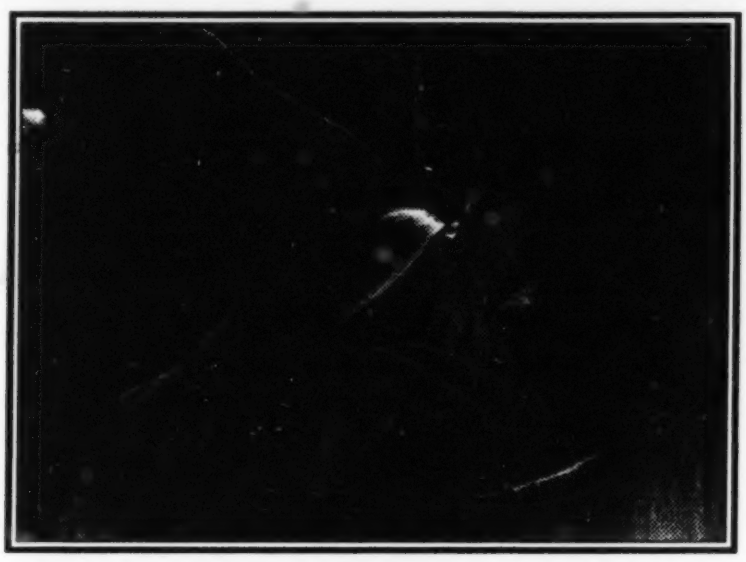
As I worked on my project and was able to visualize some of the disorientation of the disease, I also became convinced that it was important to step back from the experiences of the disease and look once again at the life that had preceded the disease. The disease was not to be denied but neither were the experiences that had preceded the onset of the disease.

Layered Worlds:
The Look of Alzheimer's

Leaf Series
Cranberry Series
Carousel Series
Window Series
A Celebration
of Layers

One panel of my exhibit was titled, *A Celebration of Layers.* In this I wanted to celebrate the many moments of time that had been as well as look at the present experience. This celebra-

tion of layers does metaphorically what the photograph album is able to do. It affirms the many moments of time, affirming the richness, the diversity. It does not allow the past to be lost no matter what the present. I found companionship in this insight in the works of other artists. I also share with them the desire that research and scientific discovery will unlock the key that will allow our perception of time to remain intact while we live through its expected movement of life and death, of past and present and future.



[1] In conjunction with the exhibit, a video interview, *The Layered World of Alzheimer's*, produced by Patricia Kane, SSJ was shown.

[2] Elie Wiesel, *The Forgotten*, New York: Summit Books, 1992, p. 13.

[3] Annie Ernaux, *A Woman's Story*, New York: Ballantine Books, 1991.

[4] The exhibit, *Helen Duke has Alzheimer's Disease*, a Photo Collage by Nicholas DeCandia was shown at the Berkshire Artisans Gallery in 1991. Another artist, Alan Gussow collaborated by creating a tape to accompany the exhibit, providing "a chatter of sound" to accompany the "visual mosaic." See *The Berkshire Eagle*, January 3, 1991 for a report of the exhibit.

[5] The booklet, *Caring and Grieving. A Mother's Story in Three Voices*, provides the narrative of their presentations at *The Politics of Caring Conference* at Emory University, Atlanta, Georgia, October 11-13, 1990.

[6] Quoted in Eleanor Rubin, *Caring and Grieving*.